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ABSTRACT

An inclusive childcare program is a program that is committed to individually appropriate practice, accepting children regardless of their developmental profiles, strengths, or competencies. This conference paper addresses the problem that although inclusive programs are now commonplace, professional childcare providers are still unsure about the limits to inclusiveness, especially in the cases of children who are Human Immuno-Deficiency Virus (HIV)-positive. The paper argues that child care facilities must face the issue of children with HIV, clarify their positions, and create policies regarding the care of children with HIV. The paper presents a scenario of a childcare facility director faced for the first time with accepting a child who is HIV-positive. Through the case study the paper argues that this problem is within the ethical domain and that relevant ethical principles must be considered in making the admission decision. Every effort to make ethically defensible decisions is critical because childcare providers will be held accountable, decisions impact on the community, and decisions reveal personal character traits. The paper further argues that using a framework for this decision, and others, allows directors to make decisions less difficult and to become better able to explain their decisions, and assists in resolving negative reactions. Includes a list of sources for information on HIV. (SD)

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INCLUSIVE CHILD CARE: AN ETHICAL PERSPECTIVE

Association for Childhood Education International
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Portland, Oregon

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Inclusive Child Care: An Ethical Perspective

There is widespread agreement among child care professionals that we ought to work with children in ways that are developmentally appropriate. The definition of developmental appropriateness in Sue Bredekamp's book includes two parts: age appropriateness and individual appropriateness.

A child care facility committed to individual appropriateness tailors its programs to suit the individual children it serves. An inclusive program is essentially a program that is committed to individually appropriate practice, accepting children regardless of their developmental profiles, strengths, or competencies. All of the community's children are welcomed and encouraged to participate, whatever their backgrounds or unique characteristics.

Implementing a policy of inclusive child care requires more than an acceptance of the ideal. Inclusive programs must provide their staff with the necessary child-specific training to enable them to effectively care for the children in their groups. Staff hesitance or reluctance to work with diverse groups of children is often based on their lack of confidence in their ability to provide quality care for atypical children. With appropriate preparation, in-service training, adequate staffing levels, and ongoing support, inclusive programs can be very effective. Inclusive programs benefit children, their families, and the community as a whole. They demonstrate respect for diversity and respect for the dignity of all individuals. Inclusive child care is a feature of a caring and compassionate community.

Inclusive programs are now the "industry standard" and child care facilities are serving children who, in the past, might have been excluded. Inclusion is the result of care providers' professional commitment to individually appropriate practice combined with increased community sensitivity to human rights issues and legislation promoting human rights. Although inclusive programs are now commonplace, we, as individuals and as a profession, are still unsure about the limits to inclusiveness. Should "inclusive" mean ALL children? Even children who are HIV-positive?

Individual care providers and child care facilities must address the issue of children with HIV. Individuals must clarify their positions and facilities must create policies regarding the care of children with HIV.

Most of the publications that address the topic of caring for children with HIV or AIDS present facts. Their intent is usually to give care providers information, to build on our knowledge of HIV and AIDS. For example, the Child Care Law Center in San Francisco has developed materials to guide us in considering our legal responsibilities to children and staff with HIV or AIDS. The legal analysis emphasizes the human rights of people with HIV or AIDS and the legal obligations of citizens and institutions to avoid discrimination. Many other organizations, including the National Pediatric & Family HIV Resource Center in Newark, New Jersey, have published materials that teach care providers scientific facts about HIV and AIDS, such as how HIV is spread and how to

prevent it from spreading in child care settings. There is abundant factual information available, much of it developed specifically for people who work with children. The materials developed by Barbara Kaiser and Judy Sklar Rasminsky are particularly helpful. I have brought along some examples of the materials that are available. I have prepared a handout listing the organizations that have produced useful information. I will distribute the handout to those who want it at the end of the session.

Many organizations have done a fine job of summarizing the medical facts for us. Although that knowledge base is essential, it is only one piece of the preparation care providers need in order to respond to the reality of HIV. Knowledge of the facts about HIV and AIDS is a necessary but insufficient basis for decision making on the job. I propose that, in addition to having factual information regarding HIV and the care of children who are HIV-positive, care providers need to recognize that the issue of caring for children with HIV is an ethical issue that can be approached from an ethical perspective. Welcoming and caring for children in an inclusive program is more than a matter of applying knowledge and demonstrating skills. It requires child care personnel to operate in the ethical domain, to confront dilemmas and make personal choices that are extremely challenging. We need more than scientific facts about HIV. We also need a framework for making decisions in the ethical domain and a high degree of self-awareness. We need to be clear about what we believe, what we value, and the personal ethical principles by which we live. We need to be able to make reasoned decisions when the options all involve negative consequences and then take responsibility for those decisions.

Caring for children involves constant decision making on the part of the care provider. All day long care providers are making curriculum decisions, child guidance decisions, and professional practice decisions. We rely on our professional expertise when making these decisions. We apply our knowledge of child development. We apply our knowledge of the research literature. We apply what we have learned about creating environments that are supportive of children's development. We also apply our ethics. Every single on-the-job decision made by care providers involves the application of ethical principles. Ethical principles are fundamental statements about how people ought to behave or treat one another. Care providers may be unclear about their personal ethics. They may be unable to put their personal ethics into words and explain or defend them to others. Care providers may be inexperienced applying a framework for ethical decision making. Regardless of our clarity, our ability to articulate our personal ethics, or our experience dealing systematically with ethical issues, caring for children places us in the ethical domain. An essential characteristic of working with children is that we are called on to make decisions that are entirely or partly in the ethical domain.

Any decision in which the welfare of people is at stake is in the ethical domain. All of the on-the-job decisions made by care providers are in the ethical domain. They all affect people. All of our choices and decisions affect someone – a child, a parent, a colleague, or ourselves. Research studies can't tell us what the right choice is when we face ethical questions. Our knowledge base isn't enough to help us choose the right course of action when someone's well-being is at stake. Facts, by themselves, provide an insufficient

basis for deciding how we ought to behave or treat one another. All of the facts in all of the booklets on HIV are, on their own, an inadequate foundation for a decision in the ethical domain. Choosing the right course of action when someone's welfare is at stake involves more than applying knowledge. Decisions in the ethical domain are based on our ideas about how people ought to behave, how we ought to treat one another, and what our obligations are to people.

The first step in making a reasonable, defensible decision in the ethical domain is to recognize that the issue you are addressing has ethical components. You might ask yourself:

- Is anyone's welfare at stake when I make this decision?
- Will anyone be affected by my decision?
- Do I have an obligation to choose one alternative rather than another?
- Is my decision based on my ideas about how I ought to behave?

At a workshop in Vancouver, British Columbia in 1994, my co-presenter and I asked a large group of front line care providers and college instructors if they could think of a single decision a care provider might make on-the-job that would not be in the ethical domain. The only example the group could come up with was the choice of the color of paint for the exterior of the building. If anyone here can generate another example of a decision a care provider might make on-the-job that is not in the ethical domain, I would like to add it to our very short list.

Care providers facing choices such as whether to care for a child known to be HIV-positive and whether to keep their knowledge of the child's HIV status confidential are clearly making decisions in the ethical domain.

We make decisions in the ethical domain on the basis of our ethical principles. These are fundamental statements about how people ought to behave or treat one another. Professional care providers need to be aware of their own personal ethical principles. These principles are the foundation for the decisions we make in the ethical domain. It is helpful to be introspective, to reflect on the principles you live by, and to be able to express clearly your personal ethics. You will, from time to time, be asked to explain and justify your decisions in the ethical domain. Supervisors, parents, or colleagues may ask you why you acted as you did, or why you chose one option over another. Part of the explanation may be your personal ethical principles – your positions on the way people ought to behave or treat one another.

Take a few moments to record one or two of your personal ethical principles – the guidelines you follow when you face decisions in the ethical domain – either in your private life or on-the-job. I will not be asking you to read your personal ethical principles to the group. You might find it helpful to use a sentence stem such as "People should always …" or "People ought to …" or "Everyone has an obligation to …"

Here are some examples of personal ethical principles. Do you accept any or all of these principles? Are your personal ethical principles compatible with these principles?

- Promote justice.

- Promote equality.
- Love and respect humanity.
- Be compassionate.
- Be truthful.
- Encourage freedom.
- Promote fairness.

Whatever your personal ethical principles may be, they will influence your decisions when you face a choice of whether to care for a child known to be HIV-positive and whether to keep your knowledge of a child's HIV status confidential.

As a member of the child care profession, your decisions will also be based on your professional ethics. Organizations such as NAEYC, and regional professional associations such as the Early Childhood Educators of British Columbia have developed codes of ethics to help their members make decisions in the ethical domain. Our professional associations recognize that we are working in a field that requires practitioners to make decisions that affect others. Our codes of ethics assist us in identifying obligations that are specific to the child care profession. Although codes of ethics are helpful, they do not reduce the difficulty inherent in making decisions in the ethical domain. A code of ethics is not a quick fix for ethical problems or a formula that will give us solutions to the ethical dilemmas that come with the territory of child care. Our codes of ethics can assist us in clarifying the issues at stake, but ultimately the individual must choose the course of action that he or she will take.

Let us work through this scenario: Zelda is the director of a child care facility with a policy of inclusiveness. One Friday afternoon a woman phones Zelda and identifies herself as Ms. Smith. Ms. Smith tells Zelda that she needs child care for her daughter. Zelda gives Ms. Smith some basic information about the facility and invites her to come by for a visit on Monday morning. After arranging the visit, Ms. Smith says to Zelda "I think I should tell you that both my daughter and I have been diagnosed HIV-positive." Zelda is surprised, but maintains her composure and tells Ms. Smith she looks forward to meeting her on Monday. Zelda has never before been asked to provide care for a child diagnosed with HIV. Zelda is glad it is Friday and she has the weekend to consider her options. First, she asks herself whether or not she should accept Ms. Smith's daughter. Zelda wonders if she should make up an excuse and tell Ms. Smith there are no openings and there is already a long waiting list. Zelda wonders if she should just say directly to Ms. Smith "I will not register your daughter because she is HIV-positive." Zelda wonders if she should just refuse to accept the child but give no reason. Would that protect her from a possible lawsuit? If she were to accept the child, how will the staff react when they find out the child is HIV-positive? How will other parents react? Don't I have an obligation to protect the other children from exposure to HIV? If she were to accept the child, should the staff be told that Ms. Smith and her daughter have been diagnosed HIV-positive? Don't they need to know so they can protect themselves? How can I keep a secret like this? Zelda goes home on Friday night feeling overwhelmed with the complexity of the decision.

All of the questions racing through Zelda's mind seem at first glance to be a confusing rat's nest of complexity. They look impossible to sort out. Probably the first reaction of many care providers in Zelda's shoes would be to try to avoid making a decision. They might ask themselves: Could this matter be spun off to the center's board of directors? Can I phone in sick on Monday morning and let the assistant director deal with Ms. Smith? Can I quit my job and get a paper route – any job that doesn't involve making hard choices? Maybe I can move across the country and start a new life in a new career? It's understandable that many care providers in Zelda's situation would wish for a way around the decision.

Although Zelda faces a difficult decision, it is not insurmountable. The challenge Zelda faces would be easier to manage if she had a framework to help her approach the problem in a systematic fashion. There are many frameworks available, designed to help us make rational decisions and explain our decisions to others. One of my favorites is the Decision Tree. It comes from a book by La Raus and Remy entitled Citizenship Decision-Making.

On the trunk of the tree we identify the decision or the choice to be made. In Zelda's case, her first decision is "Should I register Ms. Smith's daughter?" Zelda needs to know if this is a decision in the ethical domain. She can ask herself the questions we identified earlier: Is anyone's welfare at stake when I make this decision? (Yes. Ms. Smith, her daughter, employees at the center, other children, parents, Zelda) Will anyone be affected by my decision? (Yes. All of the above, plus the board of directors) Do I have an obligation to choose one alternative rather than another? (Conflicting obligations – to the Smith family, to other children, to staff, to employer) Is my decision based on my ideas about how I ought to behave? (Yes. I ought to be inclusive. I ought to protect my staff and the children. I ought to avoid lawsuits. I ought to be a caring and compassionate person.) Zelda's decision is clearly in the ethical domain. It has other elements, such as economic considerations and legal considerations, but it is definitely an ethical problem.

Having identified the problem as being in the ethical domain, the next step is to identify the relevant ethical principles that need to be considered. We can record them on the lowest branches of the tree. Let us assume that Zelda turned to some of the codes of ethics for her profession for help in identifying the relevant ethical principles. She would find in the NAEYC Code of Ethical Conduct a statement of her ethical responsibilities to children. It states " Our paramount responsibility is to provide safe, healthy, nurturing, and responsive settings for children. We are committed to supporting children's development by cherishing individual differences, by helping them learn to live and work cooperatively, and by promoting their self-esteem." Zelda would also find statements clarifying her responsibilities to colleagues: " To maintain loyalty to the program and uphold its reputation," and "To promote policies and working conditions that foster competence, well-being, and self-esteem in staff members." Zelda could list on the lowest branches of the tree these principles:

- Keep children safe and healthy.
- Promote children's self-esteem.
- Uphold the center's reputation.
- Promote the well-being of staff members.

This illustrates the dilemma Zelda faces. She has obligations to the children already in the facility, to Ms. Smith's daughter, to her employer, and to the staff.

The next step is for Zelda to imagine all the possible consequences and likely outcomes if she were to give priority to each of the principles. Let's consider them one at a time.

Suppose she were to give priority to keeping children safe and healthy and put that ahead of the other principles. What consequences might result? She might refuse to admit Ms. Smith's daughter. This would be consistent with trying to keep the other children safe and healthy. What would be the likely outcomes if Zelda did that? Ms. Smith could become very upset. She might never again inform people of her daughter's HIV status. She might sue the center and Zelda. Rejection of her daughter might trigger a crisis or tragedy in the Smith household. A public inquiry might blame the center. Zelda would feel she had not lived up to her personal ethical principles of showing love and respect for humanity and being compassionate. Can you foresee any other consequences?

Suppose she were to give priority to promoting the self-esteem of Ms. Smith's daughter. What consequences might result? Zelda might admit the child. What would be the likely outcomes of admitting her to child care? Ms. Smith would be happy. The Smith child would receive good care and her well-being would be enhanced. HIV might be spread to another child or to a staff member. If other families knew, they might remove their children from the center. The publicity would hurt the Smith family. Loss of families could bankrupt the center. Zelda would feel she had applied the center's policy of providing inclusive care. Can you foresee any other consequences?

Suppose Zelda were to give priority to upholding the center's reputation. What consequences might result? Zelda concludes that the center could get negative publicity no matter what she decides. If she refuses to admit Ms. Smith's daughter, Ms. Smith could launch a lawsuit that could hurt the center's reputation. The center would be portrayed as discriminating against people with HIV. If she admits the child and other families find out, they might publicly protest and claim the center is not protecting their children from a dangerous disease. Either way, the center may get unwanted publicity and become the focus of a divisive controversy.

Suppose Zelda were to give priority to promoting the well-being of the staff. What consequences might result? She might refuse to admit Ms. Smith's daughter. That would be consistent with trying to prevent them from being exposed to HIV. The outcomes would be the same as if Zelda had refused to admit the child for other reasons.

After listing all of the possible consequences, Zelda should classify them as positive or negative for everyone involved. What's beneficial for one party can be harmful for another party. Ethical dilemmas such as this one require us to consider the interests of many parties. Zelda's decision will affect the child who is HIV-positive, that child's family, the children already in the center, their families, the staff of the center, the owners of the center, Zelda herself, and the community as a whole. There is inherent in many decisions in the ethical domain a public interest. Our individual choices have an impact

on the kind of society we live in. They contribute to making the community a desirable place in which to live. They contribute to the community's reputation and to its place in history.

After considering all of the possible consequences of her decision, Zelda must make a decision. Her decision can be recorded at the top of the decision tree. Zelda's decision will be based on her weighing of the consequences. It will reflect her beliefs and values and her personal ethics. It will reflect her judgment. It will reflect Zelda.

Please take a moment and consider what your decision would be if you were in Zelda's position. Apply your own beliefs, values, and personal ethics to the question of accepting Ms. Smith's child in your child care facility. Please record your decision and list the factors that, for you, were most important in bringing you to the decision you made. I will not be asking you to tell the group what decisions you made or the reasons supporting your decisions.

By using a framework for our decisions, we are better able to explain our decisions than we would have been if we had flipped a coin, or pulled an alternative out of a hat. Using a framework also alerts us to what we can expect as fallout from our decisions. By definition, a dilemma will involve some negative outcomes. Having made our decisions, we must accept responsibility for the negative outcomes.

Since we don't know Zelda and we don't know what her personal values are, we don't know for sure what decision she will make. Let's assume Zelda weighed the pros and cons and eventually decided to admit Ms. Smith's daughter. Having made that choice, Zelda has a responsibility to minimize the possible negative consequences flowing from her decision. This can be done in several ways. She can begin by providing her staff with education on HIV and AIDS. She can invite parents whose children are attending the center to attend the education sessions. She can emphasize the need to follow the universal precautions to prevent the spread of HIV. She can introduce a policy of immediate notification of all families when contagious diseases such as chicken pox appear in the facility. She can develop a policy addressing staff, volunteers, and children with blisters and rashes. She can ensure that all children in the center are taught that biting is strictly forbidden. Children can be taught how to deal with cuts, scratches, and nose bleeds. They can be taught good hygiene practices and be reminded not to share their toothbrushes. Even if Zelda had decided not to admit Ms. Smith's daughter, it can be argued that she has an obligation to take these steps anyway. To meet her ethical obligation to promote the health and well-being of all children, Zelda ought to be doing all of these things: educating her staff and parents, enforcing the use of the universal precautions, and implementing policies addressing health and hygiene matters. Ms. Smith was an exceptional parent. Most parents would probably not share with a child care facility's director information regarding the child's HIV status. The extreme stigma associated with HIV, the fear and hysteria it causes, and the resulting exclusion of persons with HIV cause most parents to keep it a secret. The reality is parents don't necessarily reveal that their children are HIV-positive. There are also many undiagnosed cases. The bottom line is we don't know who is HIV-positive. Care providers need to be

acting on the assumption that any child in their facilities may be HIV-positive. That means we all need information and we all need to be practicing the universal precautions to prevent the spread of HIV. Indeed, from an ethical perspective, we have the ethical obligation to do so.

The second issue confronting Zelda is the question of confidentiality. Should Zelda share with anyone else the information Ms. Smith has shared with her regarding her own and her daughter's health? Zelda can approach that question using the same framework she used to consider the question of admitting Ms. Smith's daughter to the facility. Would each of you sketch out a decision tree for the question of confidentiality? Consider first whether or not it is an ethical issue. Then identify the relevant ethical principles. List the consequences of giving each principle priority. Classify the consequences as positive or negative for all affected parties. Then make a decision on the basis of your own beliefs, values, and ethics. Finally, list the negative outcomes for which you would have to accept responsibility if you made that decision and think about ways of possibly minimizing those negative outcomes. Given our limited time, I will ask you to finish your decision trees as homework. I hope you will make the time to work through the confidentiality question. It is not just an academic exercise. It is a real problem that all care providers will sooner or later encounter. It is somewhat easier if we are prepared for it and if we have experience using the decision-making framework.

I have brought along some copies of an excellent article entitled "Developing an HIV-AIDS Policy" by Kaiser and Rasminsky. Please pick up a copy on your way out, if you think it might be useful to you.

In the time remaining, I would like to make a few comments on the broader question of ethical child care practice. Why should we be concerned about ethics? Why should we care about making the right decisions? Why should we make a commitment to build an ethical perspective into our work? I encourage care providers and others who work with children to be mindful that they are operating in the ethical domain. We need to be aware that we are in the ethical domain and we need to make every effort to make ethically defensible decisions. Why?

- We can be held accountable. Our decisions can be questioned and scrutinized. Decisions made after carefully weighing the pros and cons of the available alternatives can be explained to those who might review our decisions. Being accountable is part of being a professional. Practicing ethically means we are better prepared to explain our choices.
- Our decisions have an impact on our communities. Ethical care providers are role models in their communities. By demonstrating a commitment to ethically defensible principles, we set a good example and help make the community a good place to live. Unethical practice breeds cynicism and distrust and reduces the quality of life in a community.
- Our decisions reveal our character. They show the world who we are and what we stand for. A commitment to ethical practice is part of the human struggle to live a good life and be a good person. Ethically defensible decisions reveal personal integrity.

Thank you for coming to this workshop. I hope it will assist you in confronting the ethical choices that come with the territory when we work with children. I welcome your comments and suggestions. Would anyone like to add to the discussion, suggest other perspectives, or share with the group helpful resources?

Sources of HIV Information

Child Care Law Center
22 Second Street, 5th Floor
San Francisco, CA 94105
Phone: (415) 495-5498

- Caring for Children with HIV or AIDS in Child Care ($12.50)
- HIV and AIDS: Employment Issues in Child Care ($12.50)

National Pediatric & Family HIV Resource Center
15 South Ninth Street
Newark, NJ 07107
Phone: (201) 268-8251 or (800) 362-0071

- HIV and AIDS in Children: Questions and Answers ($2.00)
- Getting a Head Start on HIV: A Resource Manual for Enhancing Services to HIV Affected Children in Head Start ($10.00)

Queen's Printer Bookstore
Edmonton, Alberta
Phone: (403) 427-4952

- Guidelines for Handling HIV Infection and AIDS in Day Care Services ($3.00)

McGill AIDS Centre
Montreal, Quebec
Phone: (514) 340-7536

- A Guide to Developing Policy for Children and Daycare Workers Who Are Infected with HIV (free)

National AIDS Clearinghouse
Canadian Public Health Association
1565 Carling Avenue, Suite 400
Ottawa, Ontario K1Z 8R1
Phone: (613) 725-3769

- HIV/AIDS and Child Care: Fact Book
- HIV/AIDS and Child Care: Facilitator's Guide

Also available through NAEYC 1509 16th Street, N.W., Washington, DC 20036-1426
Phone: (800) 424-2460